PSICOLOGIA
EM ESTUDO

ARTICLE 10.4025/psicolestud.v29i0.61581

A HERCULEAN SAGA: THE LIVED EXPERIENCE OF PEOPLE WITH BIPOLAR DISORDER

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ABSTRACT. The present study aims to understand the experience of people with bipolar disorder through the analysis of current scientific research that focuses on the lived experience of the participants. This mental disorder is characterized by severe mood oscillations that affect subjectivity and interpersonal relationships. Mental health professionals are concerned, since this condition is responsible for the highest rate of death by suicide in comparison to other psychiatric illnesses. This study is a meta-ethnographic systematic review of studies published in scientific journals between 2016 and 2021. Results are described using the metaphor 'Herculean Saga' which included six main meanings/concepts: 1) The first strike: loss of control of self and condemnation; 2) The first battles: the process of acceptance of the diagnosis and of the resulting vicissitudes; 3) Victory over the pit of worthlessness: the journey of recovery; 4) Meeting with enemies and friends: paradoxical support; 5) Equipment for war: weapons to face the battles and 6) Unearthed treasure: skills and strength acquired in the process of maturing. We concluded that the people with bipolar disorder live radical experiences of suffering that include the loss of control over self and experiences of exclusion and social stigma. On the other hand, understanding the illness, adhering to treatment, the persistent struggle during moments of emotional instability and an adequate support network facilitate the prospect of a process of recovery of personal autonomy.

Keywords: Meta-ethnography; lived experience; bipolar disorder.

UMA SAGA HERCÚLEA: EXPERIÊNCIA VIVIDA POR PESSOAS COM TRANSTORNO BIPOLAR

RESUMO. O presente estudo teórico objetivou compreender a experiência de pessoas portadoras de transtorno bipolar a partir da análise de pesquisas científicas atuais com foco nas experiências vividas dos participantes. Esse transtorno mental caracteriza-se por oscilações de humor graves que afetam a subjetividade e os relacionamentos interpessoais. Os profissionais da área de saúde mental preocupam-se porque esta condição é responsável pelo maior índice de morte por suicídio em relação aos demais quadros psiquiátricos. Trata-se de uma revisão sistemática metaetnográfica de pesquisas publicadas em periódicos científicos qualificados no período de 2016 a 2021. Os resultados foram descritos sob a forma de uma metáfora denominada 'Saga Hercúlea' que incluiu seis

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significados/conceitos principais: 1) O primeiro golpe: perda de controle sobre si e a condenação; 2) As primeiras batalhas: o processo de aceitação do diagnóstico e das vicissitudes decorrentes; 3) A vitória sobre o poço da desvalia: a jornada de recuperação; 4) O encontro com inimigos e amigos: o suporte paradoxal; 5) Os equipamentos de guerra: armas para enfrentar as batalhas e 6) Os tesouros encontrados: habilidades e forças adquiridas no processo de amadurecimento. Concluiu-se que as pessoas com transtorno bipolar vivem experiências radicais de sofrimento que incluem a perda de controle sobre si e vivências de exclusão e estigma social. Por outro lado, a compreensão sobre a doença, a adesão ao tratamento, a luta persistente face aos momentos de instabilidade emocional e a existência de uma rede de apoio adequada favorecem a possibilidade de um processo de recuperação da autonomia pessoal.

Palavras-chave: Metaetnografia; experiência vivida; transtorno bipolar.

UNA SAGA HERCÚLEA: EXPERIENCIA DE VIDA DE PERSONAS CON TRASTORNO BIPOLAR

RESUMEN. Este estudio tuvo como objetivo comprender la experiencia de las personas con trastorno bipolar a partir del análisis de investigaciones científicas actuales centradas en las experiencias vividas de los participantes. Este trastorno mental se caracteriza por cambios de humor severos que afectan la subjetividad y las relaciones interpersonales. Los profesionales de la salud mental están preocupados porque esta condición es responsable de la tasa más alta de muerte por suicidio en relación con otras condiciones psiquiátricas. El estudio consistió en una revisión meta-etnográfica sistemática de investigaciones publicadas en revistas científicas calificadas entre 2016 y 2021. Los resultados se describieron en forma de una metáfora denominada ‘Saga hercúlea’ que incluía seis significados / conceptos principales: 1) El primer golpe : Pérdida de control sobre uno mismo y condena; 2) Las primeras batallas: el proceso de aceptación del diagnóstico y las vicisitudes resultantes; 3) La victoria sobre Poço da Desvalia: el viaje de la recuperación; 4) Encuentro con enemigos y amigos: apoyo paradójico; 5) El equipo de guerra: armas para librar batallas y 6) Los tesoros encontrados: habilidades y fortalezas adquiridas en el proceso de maduración. Se concluyó que las personas con trastorno bipolar viven experiencias radicales de sufrimiento que incluyen pérdida de control sobre sí mismas y experiencias de exclusión y estigma social. Por otro lado, la comprensión de la enfermedad, la adherencia al tratamiento, la lucha persistente ante momentos de inestabilidad emocional y la existencia de una red de apoyo adecuada favorecen la posibilidad de un proceso de recuperación de la autonomía personal.

Palabras clave: Metaetnografía; experiencia vivida; trastorno bipolar.

Introduction

Bipolar disorder (BD) is a severe mood disorder that can be disabling and has been associated with reduced life expectancy (Laursen, 2011). Among mood disorders, BD has been one of the most studied, and prevalence estimates in the general population tend to be conservative, pointing to around 1% (Clemente et al., 2015; Goodwin, 2016). Other studies have considered less intense mood changes, increasing the spectrum of bipolarity, thus reaching a prevalence of up to 8.3% of the population (Nery-Fernandes & Miranda-Scippa, 2013). Type 1 BD is rarer, with a lifetime incidence of approximately 1% in the general population. Type 2 has the same incidence and unspecified BD has a rate of around 2.4% (Goodwin, 2016). Using the DSM-5 criteria in a North American study, unipolar depression was found to be more prevalent, around 16% (Goodwin, 2016).

This disorder has the highest rate of death by suicide compared to all other psychiatric diagnoses, with a rate of 39% per year (Pompili et al., 2013). Estimates indicate that people with bipolar disorder have a suicide mortality rate 25 times higher than the general population (Pompili et al., 2013). Goodwin and Jamison (2007) present a prevalence of suicide attempts in bipolar patients of 20-56%. A Brazilian epidemiological study evaluated 1,464 people, with rates of 20.8% suicide attempts in patients with type I BD, and 32% in those with type II BD, and 1.1% in people with other psychiatric disorders (Moreno & Andrade, 2005).

Regarding treatment, research indicates the need for long-term medication watch after a single severe manic episode, as a preventive measure because, by avoiding the occurrence of early relapses, the prognosis for the evolution of the disease tends to be better (Kessing et al., 2013). Even in a situation where the patient accepts the treatment, leading to clinical stability for several years, drug treatment must be continued indefinitely, as the risks of relapse remain high; a remission of symptoms is expected; not a cure (Goodwin, 2016). The biggest concern of psychiatrists is to reduce mania cases due to the significant negative consequences they have on the lives of patients and their families (Goodwin, 2016).

Bipolar disorder has been the subject of numerous scientific studies due to its clinical relevance (Clemente et al., 2015; Goodwin, 2016; Kessing et al., 2013; Laursen, 2011; Moreno & Andrade, 2005; Pompili et al., 2013), most of them adopting a quantitative biomedical paradigm. The present study aimed to present, through a metasynthetic systematic review, an understanding of the lived experience of people with this disorder based on two guiding questions: 1) What studies have been developed regarding the lived experience of people with bipolar disorder in the last 5 years?; 2) How are the experiences of these people described and characterized?

Method

The method adopted for this study was the meta-ethnography proposed by Noblit and Hare (1988), which consists of enabling the researcher to access elements that provide an understanding of the main concepts, meanings, and senses communicated by different qualitative studies. Kinn, Holgersen, Ekeland and Davidson (2013, p. 1287) clarify that there are several ways to propose meta-synthesis work for qualitative research, but they all "[…] represent an inductive way of comparing, contrasting, and translating the original author's understanding of key metaphors, phrases, ideas, concepts, and findings across studies". According to Campbell et al. (2011), meta-ethnography is one of the most commonly used ways to synthesize qualitative research.

A meta-ethnography seeks to produce new knowledge and not simply compile results (France et al., 2019); it seeks to go beyond individual reports and reveal analogies between studies to preserve their meaning through the selection of metaphors and main concepts. Its proponents have developed a process of 'translation' and 'translation synthesis' in which the meanings of different accounts are translated in relation to one another. "The analogies revealed in these translations are the form of the meta-ethnographic synthesis" (Noblit & Hare, 1988 p. 13). This methodology emphasizes the preservation of the meanings in studies, with translation being the element that distinguishes meta-ethnography from other methods and justifies its choice in the present study by making it possible to synthesize the lived experience of people with bipolar disorder, maintaining its complexity.

Noblit and Hare (1988) and France et al. (2019) describe seven steps to develop this methodological strategy: (1) Define the research question, objective, and focus. This study was triggered by the following guiding questions: a) What studies have been developed on the lived experience of people with bipolar disorder?; b) How are the experiences of people with bipolar disorder described and characterized?; (2) Decide what is relevant. The scope of a meta-ethnography is a crucial issue, and should be more restricted to avoid gross generalizations; (3) Make a careful reading of the selected studies to identify the main concepts; (4) Determine how studies are related, looking for relationships between common and recurring concepts. (5) Translate meanings and concepts found in each study in relation to the others. This stage includes the interpretations from the articles and the original authors' own words are used through quotation marks and paraphrases taken from the original texts so that the meanings and concepts of each study are maintained. The concepts described in the article are identified so that all of them remain faithful to the key concept; sometimes the key concept can be borrowed from one of the articles. (6) Synthesize translations; describe the path used and how certain interpretations were selected. (7) Express a synthesis; summarize the main results and compare with existing literature; reflect on the limitations, strengths, and implications of the study.

The translation and synthesis of the meanings apprehended from the selected studies are guided by the search for understanding on three increasingly deeper levels. The first level of understanding is obtained from reading the participants' lived experiences, revealing 'first-order concepts'; the second level reveals 'second-order concepts' as researchers identify, compare, and analyze the main themes or concepts present in the selected studies; and the third level reveals 'third-order concepts', created from the identification and synthesis of constructs that express the original meanings.

Article Selection Process

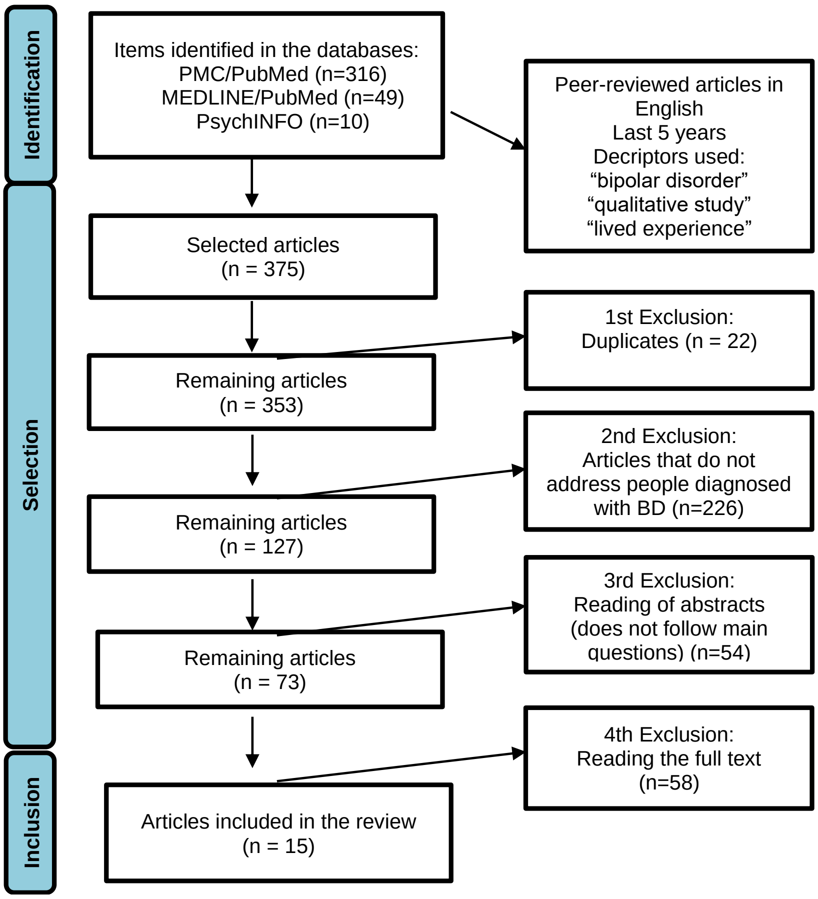
Seeking to answer the two guiding questions, a systematic search was carried out in the following databases: PMC/PubMed, MEDLINE/PubMed, and PsycINFO using the descriptors: 'Bipolar Disorder', 'Qualitative Study', and 'Lived Experience'. The time frame used was the period of five years, that is, from 2016 to 2021. In total, 375 articles were found, '10' (PsycINFO), '49' (MEDLINE/PubMed), and '316' (PMC/PubMed). After the exclusion of duplicate articles, 353 articles remained.

Inclusion / Exclusion Criteria

Initially, only original peer-reviewed articles from scientific journals in the health area, which presented research results were selected following a two-step inclusion process. Firstly, we sought to identify the best descriptors capable of identifying articles addressing the subject being researched. In the second step, we sought to carry out a screening guided by two main questions: 'Does this article contain new knowledge and was developed from research involving a qualitative method for data collection and analysis, and are the results based on the participants' experiences?', and 'Does the article focus on the lived experience of people with bipolar disorder?'.

Seeking to answer these questions, studies that did not directly address people with BD were excluded, as well as those in which the participants' diagnosis was not provided or that did not focus on this disorder. Articles in which bipolarity appeared as a secondary diagnosis, or included dual or multiple diagnoses, were also excluded. The filtering process initially took place by reading the titles, with the exclusion of 226 (remaining 127); then, filtering was carried out through the abstracts, when 54 were excluded (remaining 73); and, finally, filtering was carried out by reading the articles in full, when 58 were excluded (remaining 15). Figure 1 summarizes the process of identifying and selecting articles.

Figure 1. Flowchart: Identification, selection, and inclusion of articles in the review



Characterization of Selected Articles

Studies were conducted in the following countries: Australia, Canada, Chile, China, Ethiopia, United States, Netherlands, New Zealand (2), United Kingdom (4), Turkey, and Switzerland. The collection methods used by the authors were: individual semi-structured interviews (13) and transcription of focus groups (2). For data analysis, the following methods were used: interpretative phenomenological analysis (IPA) (4); thematic content analysis (3); social constructionism (1); analysis of themes with the help of the NVivo or MaxQDA application (2); transcendental phenomenological analysis (1); grounded Theory (1); mixed inductive-deductive approach (1); inductive thematic analysis (2).

The studies included a total of 289 participants, women and men aged 15 to 77, ranging from 7 to 49 participants in each study, with an average of 20 participants. Three studies included the participation of caregivers (22 people) in addition to people diagnosed with bipolar disorder, but without focusing on the caregivers' experience. The selected articles are described in Table 1.

Table 1. Characterization of the Articles Selected for Metasynthesis

Year/Author	Country	Sample	Method, Objective, and Analysis
2021. Perich et al.	Australia	22 to 63 years old, Women (n=29)	Individual semi-structured interviews about reproductive life experiences. Analysis based on Social Constructionism
2020. Wah et al.	United Kingdom	45 to 75 years old type I BAD and euthymic mood (n=8)	Individual semi-structured interviews about everyday risks and decisions. Interpretative Phenomenological Analysis
2020. Pallesen et al.	United Kingdom	26 to 45 years with types I and II BAD or rapid-cycling BAD (n=9)	Individual semi-structured interviews about the experience of receiving the diagnosis. Interpretative Phenomenological Analysis
2019. Tse et al.	Hong Kong	Over 18 years old, Chinese (n=32)	Individual semi-structured interviews about mental health and recovery services. Analysis: themes with NVivo
2021. Tyler et al.	United Kingdom	67 to 77 years, and family/friend of elderly people with BAD (n=7)	Facilitation of three focus groups, addressing the intervention proposal, exploring lived experience and recovery in old age. Thematic content analysis
2021. Smyth et al.	USA	18 to 25 years, diagnosed at 13 to 17 years old(n=8)	Individual semi-structured telephone interviews about symptoms, healthcare system, treatment, and support in adolescence. Analysis based on transcendental phenomenological methodology
2019. Warwick et al.	United Kingdom	People without episodes for 4+ years, living 'the life they want' (n=12)	Semi-structured interviews about perceptions of BD diagnosis and recovery. Analysis with NVivo, based on Grounded Theory
2020. Hormazábal-Salgado & Poblete-Troncoso	Chile	40 to 65 years old, Chileans with euthymic mood and preserved judgment of reality (n=7)	Semi-structured interviews about: 'What is your life experience with bipolar disorder?' Thematic analysis
2020. Crowe et al.	Nova Zelândia	21 to 55 years old, discharged no more than 3 months ago (n=11) or undergoing treatment, with cognitive difficulties (n=20)	Individual semi-structured interviews about the perception of their cognitive functioning and its impact on daily activities. Content analysis
2020. Lepouriel et al.	Switzerland	33 to 61 years old, with euthymic mood (n=22)	Individual semi-structured interviews about self-stigmatization and self-destigmatization identifying underlying aspects. Analysis from a mixed inductive-deductive approach
2018. Crowe & Inder	New Zealand	15 to 35 years old who had participated in a study on psychotherapy (n=30)	Individual semi-structured interviews about 5 years of psychotherapy experience and its impact Inductive thematic analysis
2018.	Canada	Over 19 years self-diagnosed with	Individual semi-structured interviews investigating

Morton et al.		BAD (n=43)	processes involved in the lived experience of their quality of life. Inductive thematic analysis
2018. Maassen et al.	Netherlands	Over 18 years old, with euthymic mood, and caregivers over 18 years old (n=56)	Facilitation of 7 focus groups to understand challenges experienced and implications for care delivery. Thematic analysis of data with MaxQDA.
2020. Durgu & Dulgerler	Türkiye	19 to 63 years old, with at least one hospital discharge (n=28)	Individual semi-structured interviews to understand the lived experience of recovery. Analysis with MaxQDA and Interpretive Phenomenological Analysis.
2021. Demissie et al.	Ethiopia	Ethiopian people and caregivers (one-third farmers/illiterate); 22 caregivers (wife/husband) (n=27)	Semi-structured interviews about living with the disease, coping strategies, help-seeking practices, and possible impacts. Thematic data analysis/IPA

Analysis process and results synthesis

The analysis process described by Kinn, Tanaka, Bellamy and Davidson (2018) based on Noblit and Hare (1988) was used to determine the relationship between studies and the identification of first-, second-, and third-order concepts. The selected articles were read in full, described, and characterized; then, the main results were surveyed through a list of elements that constitute the first-order concepts (literal quotes from the participants' lived experiences) and an initial survey of second-order concepts (recurrent themes added to brief descriptions of the main discoveries). Then, dimensions of contradiction and recurring issues, as well as second-order concepts, were compared and contrasted with each other (Kinn et al., 2018).

The analysis indicated that the concepts were comparable and the reciprocal translation analysis, proposed by Noblit and Hare (1988), was carried out and the concepts were mapped. Second-order concepts that related exclusively to the particularities of each study and that did not contribute to the process of synthetic understanding of the lived experiences of people suffering from BD were not considered, such as the experience of hormonal variation during pregnancy. During the process of categorizing the second-order concepts that revealed experiences of bipolar suffering, we reflected on the meanings that emerged from these categorizations, their similarity/contrast dimensions, and their relationships with the purpose of the review, considering the content as a whole. A careful thematic analysis combined with an interpretative reading of the meanings of the concepts in a synthetic way enabled the development of new general meanings of the elements present in the studies, that is, the third-order concepts. This also enabled the creation of a comprehensive metaphor.

Results

Herculean Saga

The comprehensive metaphor 'Herculean Saga' emerged from the analysis of the experiences of the 289 participants as a creative way of expressing the constant need to engage in personal battles, drowned by so much suffering, as they try to recenter themselves and continue on with their lives. This metaphor was inspired by the myth of

Hercules, the bastard son of Zeus, and a mortal woman, Alcmene (Brandão, 2009). Since his birth, Hercules suffered persecution from Hera (Zeus' legitimate wife) who, jealous, sought to harm him. She ends up driving him so crazy that it makes him kill his wife and children in a fit of rage. Under terrible guilt, Hercules, unaware of Hera's influence and fearing that he will go completely crazy, seeks help from the Oracle of Delphi to mediate the support of his half-brother, the god Apollo. A pythoness from the Oracle transmitted to him metaphorical plans that advised him that, in order to redeem himself from his terrible crime, he must become a servant, abandoning his status as a noble, and seek guidance from his envious cousin, Eurystheus. This cousin proposes a series of impossible and deadly challenges, imagining that Hercules would die in the fight (Brandão, 2009). However, as extremely difficult as the twelve labors imputed to Hercules were, he overcame them one by one; this path of confrontation through battles is symbolically considered 'the hero's journey' (Campbell, 1995). Hercules' feats became a symbol of victory through physical strength, but also intelligence, skills, and, above all, perseverance to overcome the tragedies imposed by life.

As in Hercules' life, in the articles about experiences of people with BD, we found that their struggles represented by episodes of loss of self-control and the constant struggle to recover personal autonomy and psychological reintegration throughout life. Around this fundamental experience, five other themes were found that point out important aspects experienced by these people on the journey of self-rescue, represented by a constant process of being challenged, fighting, and winning each battle in a 'hero's journey'.

1. The first strike: Loss of self-control and condemnation

Like Hercules, participants experience a loss of self-control and the subsequent guilt. Some participants referred to a loss of control over their actions, increased irritability, aggressiveness, compulsions, apathy, loss of respect for others, sleep disturbance, delusions and hallucinations, loss of autonomy, and difficulty recognizing themselves (loss of a sense of self) as agents, in their actions, identity and relationships, as a consequence of their bipolar symptoms ((Demissie, Hanlon, Ng, Fekadu, & Mayston, 2021; Durgu & Dulgerler, 2021; Perich, Fraser, & Ussher, 2021). "This disease is a nightmare for me. It's not a normal illness, it's a nightmare" (Durgu & Dulgerler, 2021, p. 3).

The dimension of loss of self-control is experienced as extreme and as frightening fluctuations in mood, difficulties in sustaining a sense of self, added to the feelings of low self-esteem, worthlessness, apathy, irritability, aggressiveness, sleep disturbances, delusions, hallucinations, among others (Demissie et al., 2021; Durgu & Dulgerler, 2021; Perich et al., 2021).

Episodes of an 'out-of-control' mood are experienced as 'scary' and generate a significant impact on both work activities and relationships (Perich et al., 2021): "I was completely out of control [...] I couldn't regulate my sleep, I couldn't hold down a job, I couldn't establish a relationship with another guy and I was embarrassed to go outside [...] and I was really afraid of what would happen to me […]" Olivia (Perich et al., 2021, p. 6).

Many participants described the feeling of being 'stuck' or 'paralyzed' because they did not feel able to think as they usually did, organize, or associate their thoughts, noticing a slowdown. "It just feels like my brain panics and it's just like I almost freeze and [...] [when I go] shopping I can't think of what I need to pick up. I can't think of how things can go together" (Woman 33) (Crowe et al., 2020, p. 324).

This leads to a loss of self-confidence, a loss of confidence in their abilities, lessened confidence in making decisions, an experience of self-stigma, shame, self-contempt, and isolation (Maassen, Regeer, Regeer, Bunders, & Kupka, 2018; Perich et al., 2021); they experience a loss of memory, concentration, organization, often leading to a lack of cognitive confidence, procrastination and difficulties in sustaining a disciplined life (Crowe et al., 2020; Morton, Michalak, Hole, Buzwell, & Murray, 2018). “When I was a student, I couldn’t attend classes properly and I couldn’t write using pen and book, like my friends” (Demissie et al., 2021, p. 6). “It was just a complete blank because my brain has just gone off somewhere else […] and you start not just having trouble making decisions about the future, you start questioning the past as well, like ‘what happened?’” (Crowe et al., 2020, p. 325, emphasis added, our translation).

They feel different from others, inferior, and ashamed (Demissie et al., 2021; Durgu & Dulgerler, 2021; Maassen et al., 2018; Tyler, Lobban, Long, & Jones, 2021; Warwick, Tai, & Mansell, 2019); they feel as if their identity is crushed or fragmented (Maassen et al., 2018; Richard-Lepouriel, Favre, Jermann, & Aubry, 2020).

2. The first battles: The process of accepting the diagnosis and the resulting vicissitudes

For the battle to begin, the warrior must face his main enemy, the reality of bipolarity. For people suffering from bipolar disorder, this is a very difficult stage and the presence of caregivers, family, and friends can be of great value at this time (Crowe & Inder, 2018; Demissie et al., 2021). The process of accepting the experience of being ill is permeated by highs and lows. Participants reported that to understand what BD means, they need to learn to talk about what they experience, talk about how they are feeling, and learn to control their mood (Crowe & Inder, 2018; Demissie et al., 2021). “I share my feelings to my sisters, brothers, and friends too and it helps me a lot. They let me know that I am not the only person who has a problem; it can happen to anyone [...] sometimes [they even] experience a similar problem” (Demissie et al., 2021, p. 4).

Acceptance of the experience of a mood disorder helps maintain a sense of self-control, a sense of empowerment (Durgu & Dulgerler, 2021; Hormazábal-Salgado & Poblete-Troncoso, 2020; Perich et al., 2021; Warwick et al., 2019), as a way of accepting reality, especially when it had been adjusted to their subjective experiences. Acceptance of the diagnosis is also experienced as one of the first steps, taking place gradually and with two sides: it can either be something that legitimizes or stigmatizes (Pallesen, Brown, Rose, & Lawrence, 2020). It can be legitimizing when it corresponds to the subjective lived experiences, contributing to an understanding of their difficulties, and helping them to find concrete solutions such as access to effective treatment (Warwick et al., 2019). “[...] without that diagnosis, you are nowhere, cause you are stuck [...] without a diagnosis, you are not getting no help, no support and it can on for years and years” (Pallesen et al., 2020, p. 361).

Acceptance can be felt as stigmatizing when it reinforces the experience of feeling diminished, overpowered by a disease, or when it promotes practices of exclusion, subjugation, or other types of violence, mainly arising from contact with third parties (Hormazábal-Salgado & Poblete-Troncoso, 2020; Pallesen et al. 2020; Richard-Lepouriel, Favre, Jermann, & Aubry, 2020; Smyth, Salloum, & Herring, 2021; Warwick et al., 2019). Participants chose to keep the diagnosis confidential (Smyth et al., 2021) for fear of being judged or discriminated against at work, making the choice to describe it as ‘depression’ or ‘exhaustion’ to avoid the term BD (Pallesen et al., 2020; Richard-Lepouriel et al., 2020).

Although providing an explanation, a diagnosis can confuse their sense of identity (Warwick et al., 2019). They feel misunderstood, alone, like ‘extraterrestrials’ compared to people who are not sick (‘I’m bipolar’) (Hormazábal-Salgado & Poblete-Troncoso, 2020), to the point that they feel excluded from the human race: “We’re not human at the extreme, we really feel like dangerous animals” (Richard-Lepouriel et al., 2020, p. 1162).

3. Victory over the pit of worthlessness: The journey of recovery

Getting out of this pit of worthlessness is not a simple or quick process. Despite being considered a serious, lifelong mental health diagnosis, there is growing evidence defying the odds of a poor prognosis since there are people with BD who are recovering. However, some participants find this concept misleading - that it must be just a stabilization, and that ‘recovery’ would be a complete remission from symptoms. “Recovery means you are recovered [...] You’re cured and bipolar can't be cured [...]” (Tyler et al., 2021, p. 6)

Participants with a more personal sense of recovery described the importance of setting goals, engaging in a meaningful activity along with medication use, self-care strategies, and the consolidation of their sense of hope (Tyler et al., 2021), being assisted, if possible, with peer support (Tse et al., 2019). Recovery is meant as a life filled with skills, abilities, and interests that are good for them; the most effective activities for recovery are those that are experienced and carried out in everyday life (Durgu & Dulgerler, 2021). In this way, participants understand the choices they make when taking risks during the euthymic phase as gestures of their true selves. In a moment of greater autonomy, when they are able to think more clearly, they evaluate more objectively the risks involved in the decisions they make. Balancing fear and avoidance is a challenge, even during euthymia, as sometimes fear prevents them from making decisions (Demissie et al., 2021; Wah, Hodge, Jones, & Algorta, 2021).

As they realize that their condition is painful and difficult but is not entirely due to the disease, they are able to accept this, a new identity, to a point that the disease no longer harms their personal identity and they feels free to lead a life without feeling sick (Maassen et al., 2018; Richard-Lepouriel et al., 2020).

4. Meeting with enemies and friends: Paradoxical support

Along the way, Hercules encounters those who support him and those who block his path. Support from family members and professionals is experienced as paradoxical (Durgu & Dulgerler, 2021; Hormazábal-Salgado & Poblete-Troncoso, 2020; Maassen et al., 2018; Smyth et al., 2021); they find something potentially healthy and/or potentially illness-inducing in those who offer them support. This is evident in the myth of Hercules who, upon receiving difficult, almost impossible guidance and tasks that were appointed by those who offered him help, the tasks enabled him to rescue himself.

As much as family members and health professionals want to help people with BD, their gestures and attitudes do not always convey support; on the contrary, some participants reported a direct correlation between the intensity of the disease and social factors, inasmuch as negative social interactions had the effect of triggering a crisis that led to a worsening of the social conflict (Demissie et al., 2021; Durgu & Dulgerler, 2021; Tyler et al., 2021). “I had an opportunity to do a three-day course and [my friends] said ‘you know you can do!’ and massively boosting my confidence. But, in fact, I know three days would be too much for me as tiredness tends to set me off" (Wah et al., 2021, p. 322, emphasis added, our translation).

Participants relate that making and maintaining friendships is difficult, and a significant stressor. They associate their experience with the disease with greater isolation and distancing from social situations; they tend to push others away and choose less stressful and safer environments, such as their own rooms (Smyth et al., 2021): "[…] a lot of friends would give up on me or people would just walk out immediately. They just don't want to deal with it, or they don't like it" (Smyth et al., 2021, p. 125).

For them, it is important to know that there are people who accept them just as they are and who care. Being able to count on someone, even if that person is in the background, helps them not feel helpless or lonely (Warwick et al., 2019). They recognize this support from family or people in the community as a motivation to become more involved and committed to treatment, participating, showing interest in knowing more about BD. When people who support them, in turn, get in touch with other professionals and help with the administration of medication, this inspires hope that better times will come and that their life has value (Hormazábal-Salgado & Poblete-Troncoso, 2020; Smyth et al., 2021). In situations of relapse, they feel that family support is fundamental, helping them put in perspective the trauma of relapse and also providing opportunities to do domestic tasks (Hormazábal-Salgado & Poblete-Troncoso, 2020).

The experience of feeling acceptance, of perceiving concrete social validation, the lack of judgment, appreciation, affirming them as persons, regardless of their diagnosis, emerged as something profoundly important, helping them in their process of self-acceptance (Maassen et al., 2018; Warwick et al., 2019).

Participants emphasized the importance of practical support, especially in the early stages of recovery, such being near mental health services, having financial support, the support from employers accommodating time off and gradual return to work. "I told [my mother] about all my suicidal thoughts, the trouble I'd been having. I opened up a lot. And she helped me get a therapist and stuff" (Smyth et al., 2021, p. 125). Support from community groups, family, and friends, online or in-person, even if people do not understand their symptoms or the course of the disease, is experienced as essential (Smyth et al., 2021; Warwick et al., 2019).

Participants pointed to the importance of open, honest, and facilitative communication with health professionals (Maassen et al., 2018; Wah et al., 2021), since they want to be treated as people and not as patients governed by the professional's knowledge and power over them (Maassen et al., 2018). A positive relationship with the healthcare professional facilitates mutual understanding, cooperation, and a feeling of being heard - preconditions for a positive experience, that promotes the BD acceptance process (Pallesen et al. 2020). Negative contact can act as a trigger, setting off episodes. One participant reported that her crises were triggered by her husband's behavior and, when he left home, her mood stabilized and she found herself stronger to deal with her BD episodes: "I no longer have that trigger so I am stable" (Tyler et al., 2021, p. 6).

The experience with mental health professionals in the therapeutic process (psychotherapy and medicalization) is seen as crucial to dealing with suffering but can also be ambiguous (Durgu & Dulgerler, 2021; Maassen et al., 2018). "Having a really good [professional], who who has given me responsibility, and believes in me, has really helped" (Tyler et al., 2021, p. 6). There are also experiences of disappointment and frustration, and the stigma related to having a life with BD can be evident in some mental health services (Durgu & Dulgerler, 2021; Maasen et al., 2018; Tyler et al., 2021; Warwick et al., 2019).

“We’re still fighting professionals who don’t believe that we are capable of what we truly are” (Tyler et al., 2021, p. 6).

While reflecting on their own experiences, elderly participants realized that their search for psychotherapy was the result of experiencing crises, influenced by negative experiences from the past; and that their progress was tied to their willingness to explore difficult topics and find the right approach and therapist (Crowe & Inder, 2018; Maassen et al., 2018; Warwick et al., 2019). They had very clear ideas about the kind of help they would like to receive: the therapist should be dedicated to building a relationship. “They need to have listening skills [...] adopting body language and tone of voice and pitch of voice [...] aware of the sort of problems we face [...] be able to get our trust” (Tyler et al., 2021, p. 7).

Despite being difficult to put into words how therapy helped, participants pointed to therapy as a place in which they can express themselves without judgment, helping them in the process of bestowing meaning to what was experienced, including difficult experiences from the past; it also helped understand their triggers, control their mood, learn to deal with difficult internal experiences and encourage being in the present (Crowe & Inder, 2018; Warwick et al., 2019). “I think the thing I took away from the therapy was an understanding of how things really affect me - the illness is as individual as the person. And the study made me aware to weak points and work around these” (Crowe & Inder, 2018, p. 4).

Peer support processes also proved to be very important as an opportunity to share experiences and knowledge about BD. “The peer support workers could feel how I feel; that is, they resonated with what in my mind, and empathized [...] [they] knew exactly what I was talking about, so I did not have to repeat my history of the last 30 years” (Tse et al., 2019, p. 6).

“They (peer support workers) had personally experienced this and knew the entire situation […] there was no hierarchy and I was able to speak my mind freely” (Tse et al., 2019, p. 6).

Not everyone sees value in peer support but many have seen effects that far exceed medication adherence, favoring the construction of recovery goals. “Peer support workers were more able to put themselves in our shoes [than other mental health professionals]. They understood the situation and what it was like to have the illness” (Tse et al., 2019, p. 7).

5. Equipment for war: Weapons to face the battles

To complete several of his tasks, Hercules used sheer strength, creativity, patience, intelligence, and self-control. To kill the carnivorous birds, he used bronze castanets he got from Athena and Hephaestus (in order to call them) and arrows soaked with the poisonous blood of the monster Hydra to destroy them. Participants also found weapons for their battles: the option of using medication, self-care strategies, and time.

Experiences with the medication were ambiguous (Maassen et al., 2018; Warwick et al., 2019). For many it was considered fundamental; others sought to suppress it with micronutrient supplements (Warwick et al., 2019). The journey towards reaching the correct dose and medication is experienced as very painful and, at times, disabling. They are seeking an adequate and satisfactory drug treatment and a correct dosage, effective and with acceptable side effects (Durgu & Dulgerler, 2021; Maassen et al., 2018). There was concern with the side effects of the medication, e.g. weight gain, feeling drowsy, and effects on memory and concentration, since these intensify as people take the medication for increasingly longer periods (Demissie et al., 2021; Maassen et al., 2018; Warwick et al., 2019). Participants who consider accepting medication as a necessary step perceive it as a decision regarding not controlling their own body, without its use. They learned over time that there was a cause-and-effect relationship between reducing the dose or decreasing medication and relapse. As a result, they realized the positive impact of medication on controlling symptoms and also that relapses could have harmful consequences (Hormazábal-Salgado & Poblete-Troncoso, 2020).

In addition to medication, the group has used other strategies over the years to manage BD, such as psychological therapies and self-care strategies. Time passing helped in this process so that, over the years, through their own experiences of living with BD and reading all the available information, management of BD became more effective. Over time, they felt better able to effectively stabilize the disease in response to mood fluctuations by identifying triggers and making conscious lifestyle changes toward greater autonomy (Crowe & Inder, 2018; Tyler et al., 2021). “I read up on it and I learned all my trigger points; I now I identify the illness, whereas before I just thought it was the way my life was going” (Tyler et al., 2021, p. 6).

6. Unearthed treasure: skills and strength acquired during the maturing process

In each of the challenges, Hercules found something that helped him successfully carry out and overcome that task. To do this he used the skills given to him, discovered his strengths, and developed them. Participants pointed to several ‘treasures’ that helped them in the process of growth in relation to the suffering they experienced: a) developing hope and a conviction of the possibility of change, as a result of being in contact with ‘normal’ people or having experiences of religious faith; b) substantial effort and persistence in trying out various possibilities until something really worked (Warwick et al., 2019); c) paying attention to small changes, as they contribute to ‘living the life they want’; d) developing an optimistic perspective when dealing with their own lives and what they have managed to build from the time of their diagnosis; e) learning self-reflection and to relate totheir own inner world; f) developing awareness of the inner dynamics of bipolarity, allowing them to identify of triggers, the very first warning signs that something is not going right, and the factors that contribute to their stabilization (Crowe & Inder, 2018; Demissie et al., 2021; Warwick et al., 2019); g) perceiving what influences their mood, identifying stressful factors in life; h) learning certain new thought patterns; i) perceiving their own values and what they want from life; j) developing an ability to tolerate and experience different feelings without being so afraid of the highs and lows in their mood (Crowe & Inder, 2018; Warwick et al., 2019); k) developing self-care through essential changes in lifestyle so as to prioritize their own well-being, finding elements in life that they would like to do (Crowe & Inder, 2018; Morton et al., 2018; Warwick et al., 2019); l) searching for work or doing something motivating, promoting a sense that they deserve to receive something good, helping to strengthen processes that reduce self-blame (Crowe & Inder, 2018; Warwick et al., 2019); m) developing their capacity of mindfulness focused on the here-and-now (Morton et al., 2018; Warwick et al., 2019); n) searching for spiritual or religious experiences such as praying, experiencing purification rites and listening to religious songs, which have had a highly beneficial influence on emotional balance, helping them feel calm and courageous when going through personal or interpersonal problems (Demissie et al., 2021).

Another important aspect of the recovery process was being able to accept significant parts of themselves, including of their selves not as a label, but as a person, overcoming self-stigma (Warwick et al., 2019). The self-destigmatization process was revealed as a way to help participants develop their own personal resources, purposes, self-management, and integration into the community (Richard-Lepouriel et al., 2020). Some participants realized that the act of comparing their circumstances with that of others with BD who have faced or are facing similar difficulties led to a reduction in self-criticism and a more compassionate attitude, which also led to a better quality of life: “Okay, this is kind of normal it happens to other people so it’s okay, just try to live with it a little bit more” (Morton et al., 2018, p. 1497).

A growing respect for the importance of others in their own lives allowed participants to be more careful with their relationships and maintain their support networks. As difficult as it was and as much as it required the development of specific techniques to maintain, the disciplined creation of a routine had significant importance in their initial motivation and in the sense of control of things, as well as in setting more realistic, achievable goals (Warwick et al., 2019). “It’s good to know where my limitations are [...] in some ways, it has been a godsend to have BD [...] I have had to learn about myself which is a really good thing” (Crowe & Inder, 2018, p. 239).

Final considerations

A ‘Herculean Saga’ as a comprehensive metaphor expresses the tragedy of people suffering from BD, as they recognize themselves as condemned to a constant experience of loss of self-control that leads to several negative consequences; at the same time, it also expresses the fact that they feel compelled to fight persistently and courageously for their recovery. In this process, significant others - family, friends, people in the community, and health professionals - appear as a crucial element that can both help and hinder, demonstrating the ambiguous dimension of support, because, when trying to help, they can, inadvertently, contribute to more suffering and trigger another crisis. Thus, a person may feel lonely because they are unable to form bonds with those who could constitute a support network, which highlights the importance of others having attitudes and skills that provide appropriate care.

One of the main skills is related to the ability to listen and understand the movement of the person who is suffering taking into account their unique needs. Sometimes, the person with BD can request help, other times the people offering support need to help them recognize their need for some type of care (Demissie et al., 2021; Durgu & Dulgerler, 2021; Tyler et al., 2021).

The experiences of guilt, fear, sadness, and worthlessness, that people with BD go through, are often associated with low self-esteem, representing a very negative experience in relation to their sense of self. In this sense, from the analysis of the material, one of the most important elements is the existence of relationships that contribute to the development of their dignity, sense of self-worth, and consideration.

Social stigma, coming from close people, health professionals, and the wider community, creates difficulties in carrying out their various activities and roles. The lack of understanding regarding people with BD was mentioned by research participants as a barrier that prevents them from expressing their feelings and seeking help, leading them to feel alone in the face of an incident of social exclusion.

People who gained experience throughout their battles while seeking a better quality of life despite bipolar disorder, revealed some significant learnings: about the need for persistence in finding a satisfactory treatment; the pursuit of optimism through attention to small steps in their progress; self-reflection and development of a relationship with their inner world, which favors the identification of the first signs of crisis and triggers, understanding what contributes or not to stabilizing their mood; acceptance of the need to take medication and careful self-observation until finding the appropriate psychotropic drug and dose; search for relationships that are not stigmatizing, that help in the development of a sense of self-dignity which assists in the development of healthy self-defense and self-care skills (this sense of dignity and self-care should be the axis on which the person guides their relationships, including relationships with health professionals); development of an ability to prioritize whatever fills their lives and activities, providing them with a sense of well-being.

In general, recovery is understood as a psychosocial process that takes place in everyday life. A positive experience of support can effectively contribute to reducing suicide rates since one of the main aspects that leads to suffering highlighted in this study is loneliness, and emotional relationships can light a flame of hope, even in the worst moments.

The meta-synthesis process showed that people with BD experience extreme experiences of suffering that range from loss of autonomy and self-control to suffering resulting from social exclusion and stigma. Two elements are fundamental to promoting self-understanding and awareness about the symptoms of the disease that affects them, enabling them to avoid further harm to themselves and others: 1) openness to accepting the diagnosis and the need to seek and adhere to specialized treatment, so that they can take care of themselves properly; 2) the existence of a support network that includes friends, family, professionals, and society/state so that they do not feel lonely and helpless. Part of this support is in obtaining knowledge about the disease; support in the process of adherence to recommended medication and psychotherapy treatment; being someone who generates trust by representing an engaged and empathetic presence, capable of putting themselves in the shoes of those who suffer, being able to help them in their quest for a better quality of life. The expected attitude is one of understanding and acceptance of the difficulties of people with BD to preserve their dignity and self-esteem amidst phases of mood swings in which they experience apathy, guilt, insecurity, anger, and impulsivity, constituting a bond of trust that allows them to feel seen and accompanied, as well as imposing limits when necessary. The person who faces the vicissitudes of this type of suffering caused by serious mood swings needs to have openness and persistence to fight for the recovery of their autonomy and find commitment and support in those whom they trust. Throughout this process, they will be able to learn considerably and will even be able to help those less experienced to face and live through this heroic saga in a lighter way and with less suffering.

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Received: Nov. 18, 2021
Approved: Oct. 06, 2022